



NATIONAL ACTION PLAN ON BREAST CANCER A Public/Private Partnership

W O R K I N G G R O U P

JANUARY 1999

THE INFORMATION ACTION COUNCIL

One of every eight women in the United States will be diagnosed with breast cancer in her lifetime. These women and those who love them have questions: What treatment approach is best for them? Should they enroll in a research clinical trial? Healthy women have questions as well: What can they do to reduce their risk of being diagnosed with breast cancer? When and how should they be screened

for breast cancer? Should they be tested to find out if they have inherited an altered breast cancer gene?

Finding accurate answers to these questions can be difficult. But new information technologies, such as the Internet, hold the promise of making information available to everyone.

The National Action Plan on Breast Cancer's (NAPBC's) Information Action Council (IAC) was formed to use new information technologies effectively to reach breast cancer patients and their families, those at increased risk for breast cancer, researchers, scientists, health care professionals, and the public. The IAC is engaged continuously in identifying strategies for using the Internet to disseminate information about breast cancer in ways that are easy to use, understandable, and useful.

CURRENT ACTIVITIES AND ACCOMPLISHMENTS

NAPBC Web Site

The centerpiece of the IAC's activities is the creation and ongoing enhancement of an NAPBC Web site on the Internet. The NAPBC home page, at <http://www.napbc.org>, provides diverse information about the NAPBC and links to other breast cancer Web sites. In addition, users can access a Spanish version of the site. More specifically, this Web site is designed to:

- *provide information about the NAPBC and its activities.*
- *support the NAPBC and its Working Groups by facilitating communication about ongoing activities and emerging issues through electronic forums.*
- *provide easy access to breast cancer information on the Internet by serving as a gateway to relevant breast cancer Web sites.*
- *encourage electronic communication among consumers, medical/research professionals, and government agencies working on breast cancer.*

WHAT IS THE NAPBC?

The National Action Plan on Breast Cancer (NAPBC) was established in 1993 in response to a National Breast Cancer Coalition petition signed by 2.6 million people and presented to President Clinton. The petition called for a coordinated national strategy to combat breast cancer, the second leading cause of cancer deaths among American women.

The mission of the NAPBC is to stimulate rapid progress in eradicating breast cancer. The strategy for the Plan is to:

- *encourage new ideas and define unaddressed breast cancer priority areas.*
- *serve as a catalyst for national efforts to advance breast cancer knowledge, research, policy, and services.*
- *mobilize partnerships and coordinate actions among diverse public and private sector organizations and individuals.*

The work of the NAPBC is guided by a Steering Committee and Working Groups. The Steering Committee provides oversight for and ensures coordination across NAPBC initiatives. The Working Groups correspond to Plan priorities and identify, recommend, and oversee implementation of Plan activities. Plan implementation is coordinated by the U.S. Public Health Service's Office on Women's Health. Currently, there are five Working Groups. This fact sheet describes the Information Action Council.

WORKING GROUP ACCOMPLISHMENTS

Developed and is maintaining an NAPBC World Wide Web site to disseminate information about the NAPBC and its activities and to serve as a gateway to breast cancer information on the Internet.



Created a Spanish language version of the NAPBC Web site.



Implemented a program of pilot projects that are using the Internet to bring information on breast cancer to informationally underserved populations.



Developed and placed on the NAPBC Web site the "Guide to Volunteering in the Fight Against Breast Cancer," which directs readers to volunteer opportunities with breast cancer advocacy organizations.

FOR MORE INFORMATION

For more information about the Information Action Council and its activities, please contact:

National Action Plan on Breast Cancer

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Bridge to Underserved Populations

IAC members also are exploring a variety of strategies using the Internet to provide hard-to-reach populations with breast cancer information. In 1997, the IAC launched the Bridging the Gap Initiative, a two-year pilot project to help informationally underserved women access breast cancer information on the Internet. Through this initiative, the IAC has built partnerships with community-based programs to provide information on breast cancer to community members, increase their utilization of this information, and expand the breast cancer-related health information network in the community. The IAC oversees the activities of the four pilot project sites, and it has developed a comprehensive plan for a multisite evaluation of the initiative.

Web-Building Toolkit

The IAC is developing a new product, Local Breast Cancer Information Resources: A Web-Building Toolkit, which will include step-by-step information, templates, resources, and referrals for developing a Web site. The purpose of the toolkit is to facilitate the formation of local Web sites and thereby fill a need for easy, low-cost access to current breast cancer information and resources. After the toolkit is tested by community-based breast cancer organizations, it will be placed on the NAPBC Web site.

FUTURE PLANS

The Information Action Council will continue to maintain and refine the NAPBC Web site to provide up-to-date information about breast cancer issues and the NAPBC. The IAC also will continue to promote the Web site to government agencies, breast cancer advocacy and patient groups, cancer centers and community cancer hospitals, the media, and consumers.

In 1999, the IAC will continue to monitor the pilot project sites of the Bridging the Gap Initiative, and it will implement the multisite evaluation of the project. The evaluation will assess the process and outcomes of the project and will delineate model program components that can be replicated in community groups across the nation.